Enabling Participation of People with Parkinson's and their caregivers in Co-Inquiry around Collectivist Health Technologies

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ABSTRACT

While user participation is central to HCI, co-inquiry takes this further by having participants direct and control research from conceptualisation to completion. We describe a co-inquiry, conducted over 16 months with a Parkinson's support group. We explored how the participation of members might be enabled across multiple stages of a research project, from the generation of research questions to the development of a prototype. Participants directed the research into developing alternative modes of information provision, resulting in 'Parkinson's Radio' — a collectivist health information service produced and edited by members of the support group. We reflect on how we supported participation at different stages of the project and the successes and challenges faced by the team. We contribute insights into the design of collectivist health technologies for this group, and discuss opportunities and tensions for conducting co-inquiry in HCI research.

Author Keywords

Co-Inquiry; Participation; Health; Parkinson's.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

AUTHORS' NOTE

This paper has been co-authored by participants who collaborated on this project. The group have paid particular attention to ensuring they have been appropriately represented in the findings. We discussed with each participant individually about their choice to be named as co-author and how this might make them identifiable. We also discussed how they would like to be identified in the paper via quotations (e.g. name, P1, pseudonym). Participants chose to use pseudonyms to protect their privacy in relation to direct quotes but agreed they would like to be named as co-authors. All signed an additional consent form to this effect and were given a copy to keep.

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INTRODUCTION

Notions of participation are heavily influential in the field of HCI. Participatory design and co-design have long been recognized as important approaches to conducting research, ensuring the people who might most benefit from new technologies are involved in the design process. Participation has been framed as a political tool in HCI, from supporting employees in improving their working conditions through the introduction of new technologies [5, 15]; promoting engagement of local people in community matters [11, 62, 63]; to empowering disenfranchised and vulnerable groups to have a say about the technologies and services that impact their lives [60]. Furthermore, there has been rapid growth in research exploring the role of digital technologies in facilitating new forms of participation beyond that of engaging citizens in design activities. For example, through participatory media generation [19], collectivist activity [10, 50], and the design of civic engagement activities [14, 31]. However, while HCI is experiencing an era of participation, it has been argued that researchers often fail to articulate how participation in projects is enabled and supported [18,61]. Furthermore, criticisms have been raised that, while participation is often referred to as an idealized good, citizens are rarely invited to engage in research until after the problems, questions and issues to be examined have been defined [61,22].

In this paper, we aim to shed light on the challenges, opportunities and practical considerations of enabling participation in all stages of HCI research; from the identification of research challenges and questions, to the development of a prototype. We report on a co-inquiry with members of a Parkinson's UK support group, in which we

explored the ways that Parkinson's care might be better supported through technology. Co-inquiry is an approach to conducting research *with* people or communities, to address matters that are important to them. 'Participants' are engaged as co-researchers, and are active in setting the research agenda and making decisions around courses of action throughout the project [4,20,22,57]. Over the course of 16 months and 10 workshops, we identified collective matters of concern with the co-research team, and initiated and completed a research project together. Following an initial scoping stage, the team directed the focus of our work towards producing an accessible health information service—later referred to as Parkinson's Radio—for the Parkinson's community. Content and ideas for our prototype were contributed by the wider support group, and used by the co-research team to produce a 'radio' show, which was then showcased to the wider group.

In this paper, we detail how the participation of co-researchers with considerable health issues, reduced mobility and anxieties around their technical, creative and research skills was enabled at key stages. We reflect on how working together, with mutual appreciation for one another's knowledge and expertise, allowed us to generate an understanding around the qualities that future tools to support community-led information commissioning and provision should have. Our contribution to the HCI community is twofold. First, we offer a set of reflections around the successes and challenges we faced when enabling participation at different stages of the research process, for future researchers wishing to study participatory modes of inquiry with people living with long-term health conditions. Second, we offer a set of considerations for the design of collectivist health technologies for such populations in the future.

RELATED WORK

Parkinson's and Digital Technology

Parkinson's is a complex condition affecting approximately 5 million worldwide [49]. Individuals can experience a multitude of possible movement symptoms (e.g. rigidity, stiffness, tremor and slowness of movement [28]), which can often be managed well through a careful combination of medications. There are also a range of psychosocial impacts of Parkinson's that can make living with the condition particularly difficult. This can include loss of independence, confidence and feelings of social stigma [8]; communication issues that can impact on socialization [41]; and the presence of anxiety and depression, alongside significant negative changes in emotional wellbeing [41,42]. In this sense, social support is particularly important. Indeed, it has been found that people with Parkinson's who report lower satisfaction with their social support networks had significantly higher levels of negative psychological state [53].

There have been a number of studies within the HCI literature that have explored the development of digital systems to support people with Parkinson's in the day to day management of their conditions [e.g. 1,2,7,13,35-40]. The vast majority of these focus on the delivery of 'treatments' or 'interventions' that focus on specific symptoms, such as gait management [2,7,35], drooling [37], motor rehabilitation [1,36], speech, [38,39] and symptom tracking [13]. Much of this literature focuses on the individual with Parkinson's and their self-directed care. Contrasting with these studies, Nunes and Fitzpatrick [47] describe the self-management of Parkinson's, and other chronic conditions, as a complex and dynamic collaborative activity that occurs between the patient-carer dyad. They call for more interest in the roles of carers and discuss the need for the development of technologies that consider carers' involvement at the core of design. This is of interest to our research, which focused on working with the support group as a collective entity.

Enabling Participation in Health Research

Historically, ageing and health-related HCI research has tended towards solutions that are influenced by new and emerging technologies. More recently, particularly as literature critical of this practice has grown [30,33,45,62], participatory approaches have resulted in more user-centered design for technologies to support ageing and health [e.g. 16,32,54,58,60,65]. Several examples of this work have deeply engaged participants throughout the design process to sensitively understand the complex settings and participant groups being explored.

For example, Thieme et al [58] describe a particularly complex project, conducted with women in a medium secure forensic hospital unit, exploring their engagement in the design of interactive artefacts to promote mindfulness. The authors describe the complexities of working within the setting and the safety, ethical and organizational issues of the research. In another project, Wallace et al [65] describe the design process surrounding an interactive art piece for a hospital specializing in severe dementia. The authors discuss the importance of stepping away from the health condition in question and taking into account the environment and people surrounding the person in order to allow for designs which allow natural interactions to emerge. Similarly, Lindsay et al [32] discuss the importance of creating an empathic relationship between designer and participants. They describe how recruitment of existing groups and caregivers can facilitate this sharing of personal narratives in a comfortable and sympathetic space. Finally, Newell et al. [46], outlined and explored a new design paradigm related to 'Designing for Dynamic Diversity' which they explain centers around an understanding that older people have significantly different and dynamically changing needs. They aimed to celebrate, rather than homogenize older people within the design process by understanding the key experiences related to ageing which might impact on technology design.

Another important point of reference concerning participatory approaches to healthcare research is Parker

		Workshop number									
Name	**Carer**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Sarah		✓	-	-	-	-	-	-	-	-	-
Daniel	Yes	✓	-	-	-	-	-	-	-	-	-
Andrew		✓	✓	✓	✓	-	-	-	✓	✓	✓
Paul		✓	✓	✓	✓	✓	✓	✓	✓	-	✓
Hazel	Yes	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Rhianon		✓	-	-	-	-	-	-	-	-	-
Larry		✓	✓	✓	✓	✓	-	✓	-	-	-
Jim		✓	✓	✓	-	-	-	-	-	-	-
Marie	Yes	✓	✓	✓	✓	✓	✓	✓	✓	-	-
Aiden		-	✓	✓	-	-	-	-	-	-	-
David		-	-	✓	-	✓	-	-	✓	✓	✓
Julia	Yes	-	-	✓	-	✓	-	-	✓	✓	✓
Jenny	Yes	-	-	-	-	✓	✓	-	-	-	-
Jeff		-	-	-	-	✓	✓	-	-	-	-
May		-	-	-	-	✓	-	-	-	-	-
Simon	Yes	-	-	-	-	✓	-	-	-	-	-

Table 1: Individual participant involvement.

and Grinter's work [50] understanding the diet-related health challenges of African Americans from lower income areas. The authors describe the design of *collectivist* health systems; in other words, 'those in which the primary goal is helping users work together to benefit the common good' (p.201). They describe how the values of collectivism (e.g. the promotion of empowerment and positivity) help nurture a sense of communal responsibility.

There are parallels here with participatory action research (PAR) (e.g. [21,34,51,55]), co-operative inquiry [3,20,22,57] and community based participatory research [3, 23-27, 43] which centrally involve participants as co-researchers in cyclical processes of action. These approaches focus on empowering communities by scaffolding and promoting their abilities as individuals. We borrow from these, to describe an approach toward conducting a co-inquiry with people with Parkinson's and their caregivers, carrying out a series of research *with* (rather than about) them. Our project involved the creation of a 'co-research team'—comprised of university researchers and Parkinson's support group members that shaped, directed and conducted the research. Although we initiated the process, it was co-directed by us and the other co-researchers. This also involved engaging a wider group of members of the support group in the generation of topics, questions and issues for the team to enquire into.

OUR STUDY

Prior to beginning our study we gained ethical approvals from both Newcastle University IRB and Parkinson's UK.

The Support Group Context

The Parkinson's support group we worked with were based in Ellington, a rural area in South East Northumberland, UK with limited ICT infrastructure. The location also means that many of the members are dispersed. Those who attend group meetings are reliant on transport (often from a carer), which can also cause issues with attendance in heavy winter weather (due to road conditions), or if specific driving members are unable to attend. The group meets on the last Wednesday of every month in a local community center. They are made up of around 36 people, although the general attendance of monthly sessions average around 25. Sessions vary in terms of content; some focus on playing games or watching entertainers; others might involve listening to research updates or information about local services. The main aim of the meetings is to provide an enjoyable, social space for people with any level of experience with Parkinson's to come together to talk, share experiences and support one another. The group focuses on providing a warm atmosphere for people to come and socialize, with members being responsive to questions when required. Although governed by a national charitable body, the group is run by the members themselves. A committee, appointed by members of the group, manage its day-to-day organization. This includes planning themes for sessions, organizing day trips, managing membership and new recruits, and creating and disseminating a monthly newsletter. Not all members of the group have Parkinson's; the group and its committee also includes carers and family members.

The Co-Researchers

The university researcher's attendance at the first group meeting was facilitated by the support group's chair and lead organizer. Prior to the first session, the chair informed all group members that a small team of researchers wished to talk to them about their experiences of research and discuss ideas for future research projects. Those interested in finding out more were invited to stay on after the end of the support group meeting (this became *workshop 1*, discussed below). After this, participation in the workshops was invited by making an announcement to the entire group following each session we attended. Members were assured that they could join and leave at any point and that prior involvement was not required in order to participate in an individual workshop.

A total of 16 members from the support group engaged in the workshops at different times of the project, participating in at least one workshop at some point over the course of the project (see Table 1 for full details). However, there was a group of 7 members (3 female carers (2 spouse, 1 daughter), and 4 males with Parkinson's) who attended over 5 workshops each. This group became the self-titled "core team". Ages of the core team ranged from 55 to 85. For the members with Parkinson's, years since diagnosis ranged from one year (n=1) to 10+ years (n=3) and each person experienced a wide range of symptoms (e.g. speech and voice issues, dyskinesia (involuntary movement), gait issues). It was this core team who were involved in the eventual co-production of the Parkinson's Radio prototype. Finally, from the University we had 3 HCI researchers, 1 with a clinical background and expertise in Parkinson's.

THE WORKSHOPS

The university researchers attended each monthly group session over the course of a 16 month period, which included day-trips where applicable. During this time, a total of 10 workshops were held, the majority of which (workshops 1-6, and 10) were held in Ellington, immediately following the regular support group. Each workshop lasted 45-90 minutes, depending on availability and fatigue of the team members. The remaining workshops (7-9) were hosted in a member's home and lasted 2 hours each.

Data Analysis

The workshops can be sectioned into three phases, each of which required different levels of engagement from the co-researchers. The first involved exploring areas of interest that the team would like to explore; the second involved ideating around these initial concepts to develop a tangible output for the project; finally, the third involved a series of co-production activities that led to the radio prototype. Workshops sessions during phase 1 and 2 were audio recorded and transcribed verbatim. Following each session, the university researchers thematically analyzed this data using an inductive approach, constructing themes from the data without any preconceived ideas of what would arise [6]. Analyses were summarized as a set of 'lessons learned' and 'what's next?' points, which were then discussed with the team at the beginning of each subsequent session, in order to validate the findings as we were moving through the project. The decision not to include participants in data analysis was made due to timing constraints—we had 1 hour monthly with the group, sometimes shorter depending on fatigue levels—and the fact that we did not want to overburden co-researchers. In phase 3, which focused on co-producing the prototype, the university researchers collected reflective field notes to inform the development of the show, and transcribed verbatim the show segments we recorded, which were then used to support in-person and remote editing activities with the co-researchers.

Below we present the methods that we used to enable participation throughout each of the phases. We discuss the subsequent findings from each phase individually to reflect the flow of our project and the iterative nature of the workshops, which was planned and designed reflexively dependent on the findings from each individual phase.

Phase 1: Concept Formulation (sessions 1 to 3)

The first phase of the work was oriented towards generating ideas for the project. In *Session 1* we adapted co-design methods by [52] to explore participants' previous experiences of 'research' and the ways in which they had participated. We used mind-mapping to explore the types of research contexts, topics and activities they had participated in, and then used visual scales to explore the levels of power, control and gain they felt they had throughout the research. After this, we used a time-lining activity to scope the research process from beginning to end, with participants questions and comments being added and responded to in whole group discussion. We ended with a series of prompted discussions around the value that research should bring and what participants considered important in future research involving them.

Session 2 focused on defining research problems and generating ideas for how we could work together to create something that would be of value for the wider Parkinson's community group (a desire which emerged from session 1). We used a series of prompt cards, which had been distributed by post and completed by participants at home, to lead the discussions. The cards asked: what would you share with someone newly diagnosed with Parkinson's?; What would you ask someone from another Parkinson's UK group?; If you ran a Parkinson's UK group for the day, what would the theme be?; What would you like to discuss with your local politician or clinician?; and what technologies do you use every day and which would you never use?. In *session 3*, three scenarios were used to explore the potential for technology to support the Parkinson's community. Scenarios reflected discussion points from the last session (relating to a need for online information services that allowed people to share experiences and find responses to questions in 'offline' ways) and probed different types of technologies which had been discussed. Scenarios included: a weekly phone in radio show; a mobile app to allow people to connect and share information about local resources or services; and a television displayed in a local Parkinson's clinics that would display responses to submitted SMS questions. This activity allowed us to navigate feasible expectations about the types of technologies and information sources we might use in our project by asking participants to visually map and discuss the positives and negatives of each idea and what would be required to make it work.

Phase 1: Findings

Identification of Research Challenges

Group members shared a range of research experiences, from involvement in clinical trials, to smaller, exploratory studies. Whilst the group discussed many positive aspects of taking part in research, such as learning new skills and gaining knowledge, they also discussed negative aspects of the current research processes they were used to. The group felt that clinical research was often conducted 'on' rather than 'with' them: *"gallons of blood being taken before and after the exercise, so obviously there are things being measured"* [Andrew], and that they were often not informed of findings: *"it hasn't happened yet…and we're not going to go and read medical journals and extract bits"* [Andrew]. The burden of participation was seen to be something that not only affected direct participants, but also the family members. Hazel explained *"he [Andrew] said he committed himself to it and was going to see it through but it had the most incredible effect on the family"*.

There was much discussion across the phase one workshops around the support group itself and the positive

impact that attending the group could have on self-understanding of Parkinson's. The team heavily advocated this as one of the benefits of the support group structure: *"I think one of the best things is being able to come to groups like this and being able to talk to each other, what I do could benefit someone else and what they do could benefit me"* [Andrew]. However, this was something that the members felt their group was not doing enough of: *"before I joined I thought this was a forum for exchanging experiences if you like. But it doesn't turn out to be that way really"* [Paul]. Jim also agreed with this sentiment: *"we don't very often talk ourselves about Parkinson's...but I think it is very important, because we're all here because of Parkinson's, what's good for me might be good for someone else"*. Andrew discussed attempting to alleviate this through the newsletter by collecting stories:

"I meant to have a quick word with people to invite some contributions for the newsletter...how I get up in the morning without falling over, things that people might have found or problems that they have that they could share, that we could help each other." [Andrew]

Hazel highlighted how, for many people, it was the social element of the group meetings that appealed to them: *"they want to company and they want the social side, which is important"*. However, it transpired that simply taking the step towards attending the group in the first place was often difficult. Andrew noted:

"I wasn't going to come along because I didn't want to see people worse than me...it's a barrier we need to get over because at the very worst it gets people together for a cup of tea and a chat, but it does much more than that".

The team described their efforts to promote the group in the wider community, but how this was often met with reservation; *"I was at the Speech Therapy group recently and told someone about the group and they said they were worried about coming because they cried easily"* [Larry]. Aiden described his effort to convince his neighbor to attend *"he won't even admit that he's got it, he won't even talk about it"*. This sense of 'sharing the burden' arose as an important message that the members wanted to share with people in the wider community.

The group also described some of the current issues relating to information seeking practices around Parkinson's related to online resources: *"we're assuming that there's all this support, that everyone will just Google Parkinson's UK and find all this wonderful information. Not everyone has access to that, how are they going to find the information?"* [Hazel]. Hazel described how many people in the group were not internet users *"we have to produce a newsletter because so many people aren't on the internet, otherwise we would send it electronically"*. But there were also seen to be issues with the paper based information resources that were available:

"It's [factsheet on medication] *written in a fairly clear style but it would say things like "this class of drug is a dopamine agonist, they work this way and there are a list of drugs that fall into this category" but that might not help the person wondering if they should up their dose of Sinemet, or if the doctor has said this then what's the significance to them"* [Andrew]

There was seen to be a need for information provision services that spoke to the needs of, particularly newly diagnosed, people with Parkinson's in intelligible ways. It was suggested that using different mediums such as video or audio could help to portray this type of information in a more accessible manner: *"someone being interviewed...trying to avoid saying it's a neurotransmitter and here is a nerve ending and a synapse"* [Andrew]. In response to these issues (people having limited chance to talk about their experiences; lack of coherent information; worry that many people in the community were not being reached) the research challenge developed by the team synthesized these points and became: *"we need an accessible, offline information resource that supports experience sharing, to help people feel that they are not alone in their problems"*.

Moving Challenges into Action

Workshop 3 explored several ideas that captured discussions from earlier sessions. It responded to the challenge of sharing information in ways that would be both broadly accessible and spoke to the qualities of the supportive environment reflected by the group (i.e. as a space to share experiences and ask questions). At this stage, radio was seen to be an option that would have the necessary reach to a wide audience of people: *"Well it would reach everyone* […] *let's face it, may not have access to a computer but most people will have access to a radio...it's such an easy thing to do, just to switch on your radio"* [Hazel]. Radio was also seen as something that would be accessible to older members: *"you can see very old people switching on their radio and listening in"* [Andrew]. Hazel elaborated: *"I think this format is particularly good for older people, who tend to have Parkinson's. A lot of the group aren't online"*.

The initial concept of a radio based information tool was seen as a recognizable format, and there was a seeming simplicity of the technology and the *"two-way interaction"* [Hazel] that it might afford. However, there were several obvious barriers towards realizing this idea within the scope of our project. First, we did not have the infrastructure required to host a show 'on the air', and the requirement that our tool be offline precluded pre-existing web platforms as impractical. As such, the team needed to reduce their expectations of what we would be able to do. To this end we considered the idea of radio as a probe, to explore how community-led information resources of this kind might be created and distributed. The following phase describes how we further explored and generated ideas around the radio design space, the challenges that were identified and the concrete ideas that emerged.

Phase 2: Ideation of Initial Concepts (sessions 4 to 6)

The second phase explored the different levels of participation that the group might have in creating a radio-style information service, and the ways in which the wider Parkinson's community (including the professionals and researcher who work with them) might be engaged in an

offering of this kind. In *session 4* a rich picture exercise [44] was used to explore the different people, processes and barriers that might be involved in creating a radio show (see figure 1). These rich pictures were created either in pairs or individually and simply began with an image of a radio in the middle. We guided the team to include in their rich picture both real people they knew (from the group) and imaginary personas who would either 'contribute to' or 'be listeners of' the radio show. This process allowed the group to conceptualize the idea visually—capturing their expectations for the project—and start to envision how a radio show might feasibly engage the wider community. The co-research team were then asked to consider themes, or topic areas, that the show might cover (which included ideas such as *"what kind of medicines are available? And what these medicines are fo*r" [Paul]*; "how can you boost energy levels when you have Parkinson's?"* [Paul]; *"off periods and medication"* [Andrew]*; "hints and tips to help PD sufferers with everyday chores"* [Larry]; and *"diet and exercise*" [Marie]). We came to the consensus that we would work on diet and exercise as the topic for our first show, as it would allow us to draw in elements of several of the other topics of interest (i.e. the effectiveness of certain medications and boosting energy).

Prior to session 5, we asked members of the wider support group to contribute (on paper) a question related to the theme of diet and exercise. These contributions became content for us to work through together during phase 3, allowing the team to ensure that the requests of the wider community were being responded to within the production phase of the show. *Sessions 5* then focused on exploring qualities of the show that the team would like to capture. We had an open discussion around the types of radio shows that the team personally listen to and some of the good and bad qualities that these had (e.g. music that reminded them of when they were younger, or talk shows on topics that they found interesting). Following this, we began to think about the type of features we would like to have in a show for people with Parkinson's, considering the contributions that had been provided by the wider support group and how these might be presented, or responded to, within a radio show format. *Session 6* then explored these ideas further, by asking team members to (prior to the workshop) listen to an *informative* radio show that they found *engaging* and note specific qualities on a worksheet (e.g. how was it organized, what made the show interesting, what was negative about it, would they listen again and why). We then compared similarities and differences between shows and selected components to translate into our own show.

Phase 2: Findings

Qualities of a 'good' radio show

The group discussed the importance of having a range of topics to *"hold interest"* [Paul] of radio audiences, which was particularly important when considering factors such as age and symptom differences: *"there are young people with Parkinson's and their needs and interests are very*

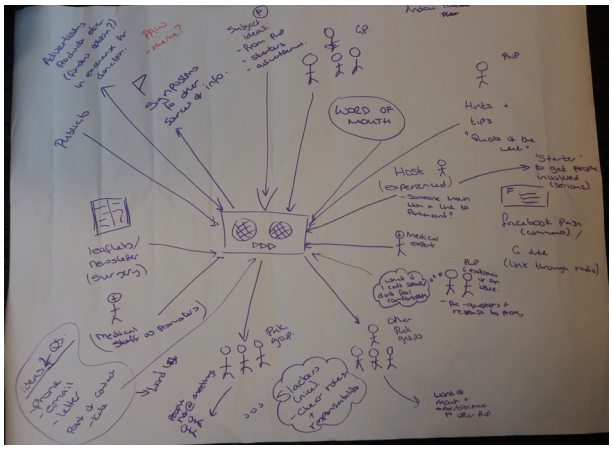

Figure 1: Rich picture description task.

different…it's not like a lot of conditions, every Parkinson's patient has different problems" [Hazel]. Shows that varied in their tone and the voices presented within them were seen to be vital for maintaining attention. Jenny noted *"I think you've got to be careful that you don't have this factual, factual and then another factual. You want to have some bits in between, so it's not so intensive"*. Hazel reiterated this: *"you've only got a certain amount of time you can concentrate on one voice"*.

However, the most important factor of an informative show was seen to be the quality of speakers who were providing factual information and advice. Speakers needed to *"talk clearly at a reasonable pace, because you sort of turn off otherwise, at the end of mine [the speaker] talked quickly and in very technical terms and I just switched off"* [Jenny]. The credibility of speakers, as experts in their field, was highlighted to ensure that advice was being appropriately given. David said: *"you need somebody qualified"*, where Jim said there is a need to *"get the facts from the people that matter"*. However, medical professionals were not automatically given trust by the group: *"some nursing staff and doctors don't have a clue about Parkinson's"* [Jim].

Other people living with Parkinson's were seen as important contributors, offering valuable personal experiences which people could relate to:

"People can relate to someone that's actually in plain speech, it gives me spots or it gives me a sore throat, you need to hear it from the symptoms aspect before it goes too complicated and they roll in slightly more exotic terminology." [Marie]

Shows that presented personal experiences from the general public with *"real patients and different types of voices"* [Jeff] were seen to add relevance to a show, by allowing listeners to relate topics to their own circumstances: *"it might work for other people who are having problems, finding out through others"* [Hazel].

Facilitating Participation

The group identified several possible issues relating particularly to speech and confidence which might be a barrier to people with Parkinson's contributing to a live show. Paul noted *"there's a confidence issue, isn't there, with Parkinson's"*. Larry, who himself experienced speech

issues, explained *"They have to be able to speak"*. Marie furthered this by saying *"you wouldn't feel comfortable, I know you wouldn't"*. There were concerns raised over the prospect of managing live contributions from the perspective of moderating content: *"there's an issue about filtering isn't there?"* [Paul]. Andrew also commented, *"if it's absolutely live and there's no filtering, who knows what you're going to get, it might be terrible or it might be brilliant"*. He also noted *"you might have somebody uttering obscenities"*. Hazel followed: *"you can't just put anybody on, can you?"*. One solution offered for this was around using carers as proxy contributors, and contributing questions before the show aired: *"you could be given the questions before the show and respond to these and someone could speak on your behalf....so it's all inclusive, it's just someone else putting something forward"* [Marie]. This idea of collating contributions prior to the show was echoed throughout the workshops, with ideas such as email, post, and telephone contributions being put forward. There was importance placed on having a range of mediums that would allow for the contribution of questions to be facilitated; however, it became clear that attempting to manage these in-situ as the show was 'airing' could be difficult. As the workshops progressed, it became clear that the option of pre-recording a show would be work best.

There were also a set of tensions and concerns, shared amongst the group, surrounding who would present the show and how the team would contribute to the production of the show. Whilst they were all willing to discuss their own experiences of Parkinson's, and indeed this was where their comfort and expertise lay, no one felt that they would have the skills or confidence to interview an expert or provide the cohesive voice that would tie the show together. The team placed much importance on having a *"confident presenter*" who *"knows what they are doing"*. As we will discuss in the following section, the university researchers were leaned upon to provide this element.

Phase 3: Co-Production of Show (sessions 7 to 10)

Our final phase focused on the co-production of the radio show which, in response to concerns around 'liveness', was pre-recorded. For *session 7* we revisited the questions submitted by support group members. We first ranked these in terms of importance, considering who the response might benefit most. We then explored how questions might be responded to within our show (i.e. through listening to personal experiences, or direct response from an expert). *Session 8* then involved paper prototyping the show. We provided the team with two personas; one a particularly engaged support group member (presented as an active contributor to the show) and the other a wary, newly diagnosed person with Parkinson's who did not attend meetings and would not submit a contribution (reflecting the disengaged wider community that the group hoped to reach). The group were given a set of prompt cards to respond to, asking them to identify 4 things their persona would like to hear in different show segments (e.g. personal experiences from people with Parkinson's; Q&A with experts; factual information about Parkinson's and its symptoms). We then filled out similar cards for the show's introduction and ending. During this workshop we also selected 3 questions that would prompt discussion in a 'personal experiences' segment, and identified who we would like our expert speakers to be. Suggestions were mainly Parkinson's specialists that the team had contact with, or researchers in the area that they heard speaking at events. The university researchers were tasked with contacting experts to request participation in the show.

Figure2: Editing activity during co-production phase.

The final two sessions both involved recording and editing the show. We first completed the personal experiences segments. At *session 8*, the team members with Parkinson's took part in a recorded discussion around their experiences of diet and exercise, structured around the prompts created in session 8. We also revisited the commissioned questions from the wider support group and monitored whether or not they were being responded to. To do this, the carers (who were listening to the discussion as it was being recorded) made notes of whether or not they felt the questions had been answered. Any questions that were not addressed were flagged up to be addressed directly to the experts.

Due to the fact that we were conducting the project in a rural area, and in respect for the expert's time and challenges around long journeys for some of the team members, it was agreed that the university researchers would travel to the experts' workplaces to conduct the interviews. Experts were provided with transcripts of the personal experiences segments, which were edited by the group for content (removing instances where topics had digressed). We focused the interview questions on the main topics of conversation that arose during the personal experiences segments (issues with protein for medication uptake, issues with bowel movements, weight loss, experiences of conductive education (a physical therapy program), local research trials, and suitable exercises for people with Parkinson's) and interweaved the remaining

unanswered commissioned questions (e.g. 'how many calories should people be aiming for daily?'). Following the completion of the interview, we took all of the recordings back to the team for editing.

Session 9 involved editing the audio to finalize the show. We played the team each of the interviews and asked them to hold up a stop sign (see figure 2) when they had an editorial comment to make. Inspired by [16] we adopted a keep, lose, change approach that guided the team to make comments on sections they felt were particularly good, unnecessary (e.g. repeated information, poor answer, long pauses) or poor quality. Following this session, the university team edited the segments and sent the finalized version to the team for comments. The entire process concluded by showcasing the show to the wider Parkinson's support group, which became *session 10*. We played the show to everyone at their regular meeting and asked members to make notes on a set of cards, relating to sections of the show that they found: 1) relevant to themselves, 2) where they felt they could add their own experience or knowledge, 3) where they felt a question they had submitted had been answered, 4) that they felt they would like to share with someone else, and 5) that they felt they would like to remove. Members then broke into small groups, facilitated by the research team, where their thoughts on the usefulness and relevance of the show to them were discussed. They also discussed how they felt this type of radio-style show, as an information resource, could best be shared with members of the wider Parkinson's community, especially those unable, or unwilling, to attend to support group meetings.

Phase 3: Findings

Managing and Prioritizing Contributions

Within this theme there were two main issues that emerged. Firstly, there was the difficulty that participants faced around wanting to be inclusive, and feeling as though they had a moral responsibility to ensure that *every* voice was heard and that everyone's questions were responded to. Whilst this was feasible within the context of our show, translating this contribution commissioning exercise to a larger audience was imagined to be a significant challenge by the team. This then gave rise to the second issue that emerged within this theme, which centered around maintaining the participation of people who had fluctuating and, for many, degenerative symptoms. There was a level of concern surrounding the fact that large tasks like this might be delegated to more active people within the support group, who already put much of their time into the running and organization of the sessions. At the same time, the transient nature of symptoms in Parkinson's was seen to make it difficult for less able members to take responsibility of these large activities. Indeed, we saw first-hand how fluctuating Parkinson's symptoms could impact on general participation of group activities. As seen in table 1, there were several team members who attended only one session. For some, it was simply reliance on others to provide transport from the support group, which made remaining later, in order to take part, difficult. For two members (Larry and Jim) who contributed heavily in the initial, exploratory phases, they withdrew due to diminishing health. As such, the core group who took responsibility for the planning and co-production of the project prototype represented a relatively motivated and 'able' cross section of the support group (although we did see our share of health complications and instances of fatigue within the core group too). Many members of the team were part of the support group committee (i.e. the chair, the treasurer and the newsletter creator), responsible for the planning and delivery of the monthly sessions. Thus, the time and effort they were already putting in to support the group were particularly high.

Creating and Editing media

When creating media for the personal experiences segment the group were clear that they wanted this to be free-flowing and 'chatty', to represent a portal into their support group sessions—for those who were unable, or unwilling, to attend these—and the types of discussions that naturally arose there between members: *"One of the good things about our group is that you'll chat to people and realize they're having a similar problem to you."* [Andrew]. However, this caused some challenges during the editing phase. Due to issues with low volume and vocal clarity, one of the speakers who contributed to the personal experiences segment was particularly quiet in the recording, despite us using separate audio recorders to capture each speaker. As such, we were required to amplify his voice significantly which caused issues with the overall quality of the segment. Although this person was generally easy to understand in day-to-day life, his voice did not translate well to recorded media. In addition, due to the informal setting of this discussion, there were sections of the recording which digressed to specific people the team knew in the local community. While conversation was jovial, and nothing was thought of the discussion as it was being recorded, it was felt upon listening back that, out of context, some comments could be perceived as offensive. These points provide important insights into the issues that can arise in non-professional media production.

Showcase Feedback

When the final prototype was showcased back to the wider support group it was met with enthusiasm, with listeners finding the content of the show interesting and relevant. The group felt the resource would be particularly useful for people how had been newly diagnosed with Parkinson's:

> *"I think it would be really good for people who are newly diagnosed, who don't necessarily want to come to group who want as much information as possible but don't necessarily want to be faced with what they perceive as what they could become in the future"* [Annette].

Similarly, the resource was seen as something that would support *"isolated people"* within the community, who were not part of the support group.

However, it became clear during the discussions that accessing these types of people could potentially be difficult. David explained *"I know people I've met in the pub and in the street and that, but I don't know their names"*. This highlighted the somewhat closed social network of the Parkinson's support groups and the isolation from the Parkinson's community that people who do not, or cannot, attend the group meetings might face: *"not many people come to group compared with the amount of people who've been diagnosed"* [Kelly]. There were however, several suggestions relating to how the show might reach people outside of the support group context. For example, playing it in the Parkinson's clinic waiting room (Kelly), having clinical staff promote it (Annette & Sheila), or putting posters up in GP clinics (Kelly).

DISCUSSION

Through a process of co-inquiry we have explored how the design and creation of digital media can support the exchange of information, advice and experiences related to Parkinson's. In doing so, we have highlighted some of the key qualities of health-related information and support that are valued by those in the Parkinson's community. Furthermore, through our cooperative mode of inquiry we have also highlighted the opportunities and challenges of involving members of a Parkinson's support group as co-researchers and co-producers of audio media. In the following we reflect on three key considerations for future research. These highlight the ways that future systems might support community-led information services and how they might reflect the collectivist values we observed in the support group context.

Enabling Participation in Co-Inquiry

As we saw from discussion around participants' experiences of previous research, their role in health-related research was most frequently as a test-subject, with processes being conducted 'on' them. They also highlighted the inaccessibility of clinical research outputs, which are often written up for the clinical and academic communities. The need to involve participants more centrally in discussions around, and design of, research is acknowledged, with Patient and Public Involvement (PPI) requirements forming part of clinical funding procedures for many research councils. However, work critical of PPI has highlighted the often 'tokenistic' involvement of participants in this process [48], and calls for improvements to the way the clinical community view participation and the value of clinical communities in providing expertise through lived experience. There is much that can be learned from approaches to community based participatory research (CBPR) in the field of public health [23-27] around how to engage clinical populations more centrally in the design, conduct and dissemination of research. For example, Israel et al [23] provide a series of policy recommendations for increasing CBPR, including improvements to funding for research partnerships—such as planning grants to allow time for researchers to establish trusted working partnerships with communities, and funding which could be provided directly to community organizations to allow for a more balanced distribution of power dynamic amongst research partners. They also call for considerations around capacity building and training for CBPR partners, and reward structures that compensate for community partners' time.

In our work we have shown how (with a level of flexibility and a willingness to adapt to fluctuating levels of motivation, fatigue and skill) participation in shaping research directions and its outputs can be enabled. Our co-inquiry led to a continual re-negotiation and realization of what the research challenges and questions were; shifting mindsets from "being researched" to "being researchers". Whilst this continuous learning and re-orientation of the project was challenging, it highlights opportunities for HCI. Firstly, it is necessary that we, as a research community, do more to disseminate our results in accessible ways to our participants (no matter what type of research we are conducting). Throughout our project we were able to and co-create a set of tangible outputs from the work we had completed together (our show, this paper, and a write up for the Parkinson's UK newsletter). Secondly, when designing with support groups with dispersed and irregular membership, we need to consider methods, and future interfaces, systems and technologies that promote the sharing of information and experiences in a range of different ways. This might involve thinking of solutions which do not require the internet, particularly when considering working within rural areas with a largely older population. Third, our work also highlights the value of engaging in co-operative inquiry over extended periods of time, helping us to avoid moving immediately to simplistic techno-centric solutions to complicated problems [30,33,45,62].

Through our co-inquiry process, we were able to draw several insights which could be applied to future work, and the design of health information tools which speak to the values participants expressed. Below, we highlight opportunities for future systems to support participation through content commissioning and co-production.

Supporting a Range of Contributions

The support group we worked with was inherently collectivist in its attitudes towards supporting one another, placing great emphasis on ensuring that the needs of their community were met throughout the course of the project [50]. There was a sense of advocacy for others that came through during the identification of the research challenges, with the team preferring to focus on others within the local community who had less support than themselves. This advocacy within the Parkinson's

community has also been noted by other researchers [62,66], where 'lead' participants incited excitement around a project and prompted others to take part. In this sense, the seemingly close knit nature of local Parkinson's communities could be leveraged to drive forward future promotion of these types of information systems and motivate other groups to create their own media content.

However, we also highlighted concerns around the fact that these activities might be taken up, or indeed left to, more active and able volunteers who are already heavily engaged in shaping the community. While we attempted to support a range of voices within the process of our project, by commissioning content ideas from the wider community, there were concerns that if this were to become a larger scale endeavor, over shorter periods of time, then management of input might become particularly difficult. There is a need for future systems to support the flow of information and contributions into information services like these. In this sense, digital technology has the potential to support these practices by automating some of the more complex tasks, such as managing large amounts of contributions. For example, crowdsourcing could be a way to group similar questions together, reducing the amount of contributions to work through, [9] and digitized voting systems could be a way to democratize the types of shows people want to hear about most and the types of questions that they would like to have answered [64]. However, as noted in Vines et al [61], there are often multiple different configurations of participation. The authors argue that there is a requirement to acknowledge the micro contributions that exist within community-led research. In our case, this could simply be appreciating the fact that simply being a member of the support group which has created the content, could lead to the inspiration of topics, discussion and sharing of stories. As such, we need to be careful that future systems do not force specific types of contribution, but allow for a range of people to remain involved, whether this be simply through listening to and discussing the show with others, There is a need for the consideration for future technologies which bridge, rather than replace, online and offline social support systems [59].

Enabling participatory co-production

We faced several complex challenges, particularly in co-producing the show. First, while this was framed as a co-inquiry, the university researchers still initiated the idea of the project and heavily facilitated the early sessions. Early on, the project was met with some reservation by the co-research team due to their perceived lack of skills and confidence. The university researchers also conducted the final editing of the show. While we aimed not to impose our own agenda upon the edit and only made edits that had been discussed during the editing workshop (session 10), this highlights challenges associated with skills development and a perceived high barrier to entry. We managed to facilitate participation in these types of editing activities, to a degree, through paper and discussion based activities. However, there is a need for future work to be mindful of supporting ways to facilitate the participation of non-experts in tasks requiring particular technical skills, to enhance a greater sense of ownership over the media being created. Recent work has looked at supporting co-production with non-experts. For example, Green et al. [19] highlight the challenge of engaging non-professional participants in professional film-making activities and argue that streamlining media into a linear narrative can undervalue diverse perspectives. They call for a more fundamentally *design-oriented* approach to media-making, which, they explain, can take different forms outside the confines of mainstream broadcast distribution.

There were also several concerns around how the show might reach those isolated members of the community, which was the original ambition of the work as defined by the co-research team. In this sense, the pre-recorded show served as a prototype for an actual community radio offering (i.e. received over a radio set). There have been recent movements within HCI which could support the distribution of such radio style offerings. For example, several researchers have studied the use of telephony based radio within rural areas of developing counties [12,29,56], wherein radio shows can be accessed via the telephone by calling a particular number. This could certainly be applied to our work and the work of other researchers focusing on particularly 'offline' health communities.

CONCLUSION

In this paper we described a co-inquiry conducted in collaboration with members of a Parkinson's support group. We outlined the generation of a research challenge, which focused on creating accessible, offline information resources that allow people to share experiences of Parkinson's and ask questions surrounding a range of topics. Our reflections provide unique insights into the challenges and successes that co-inquiry can elicit. Further work is required to explore how systems might support the creation of community information services in the future. The fact that participants were not involved in the data collection or analysis during the project is a limitation of this work, yet a reality of working with participants who might be prone to fatigue or ill health. However, future work of this kind could consider lightweight methods for enhancing engagement within these types of research activities. There is a possibility that encouraging participants to take and share notes during and between workshops could be an approach to take in the future.

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